

National Organization for Rare Disorders, Inc.®

MEMBER ORGANIZATIONS

Alpha One Antitrypsin Deficiency National Association
Alpha One Foundation
ALS Association
American Brain Tumor Association
American Laryngeal Papilloma Foundation
American Porphyria Foundation
American Syringomyelia Alliance Project
Aplastic Anemia Foundation of America
Association for Glycogen Storage Disease
Association of Gastrointestinal Motility Disorder, Inc.
Batten Disease Support & Research Association
Benign Essential Blepharospasm Research Foundation, Inc.
Charcot-Marie-Tooth Association
Chromosome 18 Registry and Research Society
Cleft Palate Foundation
Cornelia de Lange Syndrome Foundation, Inc.
Cystinosis Foundation, Inc.
Dysautonomia Foundation, Inc.
Dystonia Medical Research Foundation
Dystrophic Epidermolysis Bullosa Research Association (D.E.B.R.A.)
Ehlers-Danlos National Foundation
Epilepsy Foundation of America
Families of Spinal Muscular Atrophy
Foundation Fighting Blindness
Foundation for Ichthyosis & Related Skin Types (F.I.R.S.T.)
Genetic Alliance
Guillain-Barre Syndrome Foundation International
HHT Foundation International, Inc.
Hemochromatosis Foundation, Inc.
Hereditary Disease Foundation
Histiocytosis Association of America
Huntington's Disease Society of America, Inc.
Immune Deficiency Foundation
International Fibrodysplasia Ossificans Progressiva (FOP) Association, Inc.
International Joseph Diseases Foundation, Inc.
International Rett Syndrome Association
Interstitial Cystitis Association of America, Inc.
Lowe Syndrome Association
Mastocytosis Society
Myasthenia Gravis Foundation
Myeloproliferative Disease Research Center
Myositis Association of America
Mucopolidosis Type IV Foundation (ML4)
Narcolepsy Network, Inc.
National Adrenal Diseases Foundation
National Alopecia Areata Foundation
National Ataxia Foundation
National Foundation for Ectodermal Dysplasias
National Hemophilia Foundation
National Incontinentia Pigmenti Foundation
National Marfan Foundation
National Mucopolysaccharidoses Society, Inc.
National Multiple Sclerosis Society
National Neurofibromatosis Foundation
National PKU News
National Sjogren's Syndrome Association
National Spasmodic Torticollis Association
National Tay-Sachs & Allied Diseases Association, Inc.
National Urea Cycle Disorders Foundation
Neurofibromatosis, Inc.
Osteogenesis Imperfecta Foundation
Parkinson's Disease Foundation, Inc.
Prader-Willi Syndrome Association
Pulmonary Hypertension Association
PXE International, Inc.
Reflex Sympathetic Dystrophy Syndrome Association
Scleroderma Foundation, Inc.
Sickle Cell Disease Association of America, Inc.
Sturge Weber Foundation
The Paget Foundation
The Steven Johnson Foundation
Tourette Syndrome Association, Inc.
Trigeminal Neuralgia Association
United Leukodystrophy Foundation, Inc.
United Mitochondrial Disease Foundation
VHL Family Alliance
Wegener's Granulomatosis Support Group, Inc.
Williams Syndrome Association
Wilson's Disease Association

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... out of the darkness,
into the light ...

June 18, 2001

The Honorable John D. Dingell, Ranking Member
House Energy and Commerce Committee
U.S. House of Representatives
Washington, DC 20516

Dear Mr. Dingell:

The National Organization for Rare Disorders (NORD) applauds your efforts to ensure passage of the *Bipartisan Patient Protection Act of 2001*. This legislation must be enacted by Congress to guarantee that all Americans have access to timely and appropriate medical care.

There are approximately 25 million men, women and children in the United States suffering with rare disorders, many of whom are denied access to quality healthcare coverage, because managed care organizations may deny benefits due to low demand, unfamiliarity with standards of care for unusual diagnoses, and/or the high cost of care. When benefits are denied and there is no appeals process, patients continue to suffer unnecessarily because there are no safeguards to insure the fair and unbiased resolution of appeals. Continuity of care and access to clinical trials is also of significant importance to those suffering with the 6,000 known rare "orphan" diseases.

On behalf of the voluntary health organizations and the thousands of individual patients, clinical researchers and healthcare providers represented by NORD, we wholeheartedly endorse your efforts to enact the *Bipartisan Patient Protection Act of 2001*.

Sincerely,

Abbey S. Meyers
President

Associate Members

Acid Maltase Deficiency Association
ALS Association/Greater Philadelphia Chapter
American Autoimmune Related Diseases Association
American Behcet's Disease Association, Inc.
American Self-Help Clearinghouse
Angel view Crippled Children's Foundation
Ataxia Telangiectasia Children's Project
CGGS Family Network
Canadian Organization for Rare Disorders

Children's Living with Inherited Metabolic Diseases
Children's Medical Library
Children's PKU Network
Chromosome Deletion Outreach, Inc.
Chronic Granulomatous Disease Association, Inc.
Consortium of Multiple Sclerosis Centers
Contact A Family
Cooley's Anemia Foundation
Cushing Support & Research Foundation
Family Caregiver Alliance
Family Support System for North Carolina

Freeman-Sheldon Parent Support Group
Hydrocephalus Association
International Foundation for Alternating Hemiplegia of Childhood
Klippel-Trenaunay Support Group
Late Onset Tay-Sachs Foundation
Les Turner ALS Foundation, Inc.
National Association for Pseudoxanthoma Elasticum
National Gaucher Foundation
National Lymphedema Network
National Niemann-Pick Disease Foundation

National Patient Air Transport Helpline
National Spasmodic Dysphonia Association
Organic Academic Association
Osteoporosis and Related Bone Diseases National Resource Center
Parents Available to Help (PATH)
Parent to Parent of New Zealand
Rare and Expensive Disease Management Program
Recurrent Respiratory Papillomatosis Foundation
Restless Legs Syndrome Foundation
Sarcoid Networking Association

Shwachman Syndrome Support Group
Sickle Cell Disease Association of Texas Gulf Coast
Society For Progressive Supranuclear Palsy, Inc.
Sotos Syndrome Support Association
Takayasu's Arteritis Association
Taiwan Foundation for Rare Disorders
Treacher Collins Foundation

Associations are joining continuously. For newest listing, please contact the NORD office.

Dedicated to Helping People with Orphan Diseases